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ABSTRACT

This study identified critical factors in two states as they begin to develop family centered policies for the Infant and Toddlers Program as required by Part H of the Individuals with Disabilities Education Act. It focused on the Individual Family Service Plan, the identification of families' strengths and needs, and case management. Data were gathered through structured on site interviews with various state agency personnel. In the first state, implementation has been primarily an effort of a single lead agency while in the other implementation efforts have stressed shared interagency responsibilities. After an executive summary and introduction, the study's methodology is detailed, and the results summarized for the following areas: family strengths and needs, entitlement issues, and service coordination. Five major recommendations were made. These are: (1) states should reexamine their structures for providing early intervention services; (2) families, advocates, and providers should be fully informed of the issues and options involved in providing early intervention services; (3) multiple vehicles are needed for input from the local level to reach state policy makers; (4) the multiple agencies that provide services to this population should be identified and invested with authority; and (5) personnel from all strata of program implementation and policy making should be involved. (13 references) (DB)

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Carolina Institute for Child and Family Policy

Part H Policy Development for Families: A Case Study Report

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EC 300170

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for Families: A Case Study Report

Patricia Place
James J. Gallagher

February 1992

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EXECUTIVE SUMMARY

This study, conducted by staff members of the Carolina Policy Studies Project (CPSP), identifies critical factors in two states as they begin to develop family-centered policies for the Infant and Toddlers Program (Part H of IDEA). The study has focused on the policies the states have developed that most directly have an impact on families of young children with disabilities: the Individual Family Service Plan, the identification of families' strengths and needs, and case management. Data were gathered through structured on-site interviews with a variety of state agency personnel.

Two states were selected to serve as contrasting cases for this study. These states will be referred to in this report as "Fox" and "Charlie." In one state, Fox, the implementation of the early intervention system is, and has been, primarily an effort carried out by a single lead agency. In the second state, Charlie, efforts are, and have been, guided by a philosophy and practice of shared interagency responsibilities.

Identification of Family Strengths and Needs. Emerging best practice in the field of early intervention has progressed to the point where family members have a vital role in identifying their family's needs and strengths. This is a fundamental change from the traditional approach of relying on professionals to assess families' strengths and needs.

Fox used an outside consultant and pilot projects to attempt to change the philosophical approach that early intervention staff, under the authority of the lead agency, currently were using to identify the strengths and needs of families. State agency representatives hoped that the early intervention programs would move from the philosophy that parents were targets of intervention to realization that parents were equal partners in decision-making

about early intervention. This change was expected to be difficult for staff who were used to, or preferred, operating under the traditional clinical philosophy of treating the child as a patient or client and parents as needy and passive.

At the time of the site visit to Charlie, people from a multitude of agencies were conducting activities to identify a family's strengths and needs. An unintended result of having many professionals conducting these types of activities was that the processes of identifying family strengths and needs were fragmented or duplicated. The goals espoused by the great majority of interviewees were to correct and equalize for some, and shortchange for others the identification of family strengths and needs..

Entitlement Issues. The Part H statute does not make explicit the services to which the infant and toddler and their families are entitled. This is to be determined on an individual basis, and is to be described in each Individualized Family Service Plan (IFSP) that is developed for each eligible infant and toddler. Given that family services, as required by Part H, are somewhat new services under the 1986 amendments to the Education of All Handicapped Children Act, state policy makers are uncertain about which services a family is entitled to under this program. Most states want to assist families to obtain all the services the family needs but, in reality, the services required under the Part H program must be delimited in some way because of the scarcity of resources at the state and local levels and the minimal funding provided at the federal level.

Differences in the consistency of responses to family policy development among those interviewed in Fox, as compared to those interviewed in Charlie, was an interesting finding. While Fox interviewees showed cohesion on the question of entitled services, the Charlie interviewees varied greatly on the topic. The Interagency Coordinating Council (ICC), providers, parents, and

agency personnel in Charlie had engaged in frequent discussions with each other about the topic of "entitlement of services." This state had developed written policies about the services to which a family was entitled. Yet in the vignette, Charlie's interviewees expressed widely divergent opinions about the services to which a family was entitled.

Meanwhile, in Fox, a state that appeared to have had little systematic discussion about the area of services entitlement, the opinions of the interviewees showed remarkable consistency. This consistency may be a result of the structure for the planning and implementation for Part H. The early intervention program in Fox is a relatively straightforward system carried out primarily through a single agency, and minor changes in practices were expected as a result of the passage of Part H. Perhaps this more simplified approach facilitates understanding of policies between those at the policy planning level and those providing and receiving the services.

The early intervention system in Charlie was much more complex, involving many more agencies and constituencies. Furthermore, Charlie was entertaining the concept that the changes brought about as a result of Part H would lead to moderate systems change, not refinement of existing policies and practices. Charlie's planning focus involved far more constituencies. Concomitantly, interviewees displayed far greater diversity of opinions about entitlement.

Case Management. The Part H program requires that states offer families the option of identifying the families' strengths and needs. The case manager is charged with assisting families in meeting these needs. Case management decisions will serve as an anchor for families who interact with the early intervention system and are vital to the success of this program.

Interviewees in Fox focused on the need to make changes in professionals' attitudes towards families, such as promoting a change from considering the family a passive recipient of services to viewing families as basically competent and only sometimes needing outside assistance. Otherwise, the goal appeared to be to continue to do what had been done (i.e., have the early intervention staff provide what case management they could, given their therapy schedules and other work assignments).

In contrast, the goals for case management in Charlie reflected the desire on the part of the interviewees to develop a family focused system that transcended agency boundaries. There was a dynamic tension on the part of providers between wanting to do things the way they thought best and recognizing the need for state policies to avoid fragmentation and duplication of services and to ensure equity to all families throughout the state. Often, interviewees requested guidance from the state about how to conduct case management activities that would still allow providers some flexibility within this guidance.

The passage of Part H legislation brought states with established early intervention systems face to face with two options. First, they could continue on the course established by the state prior to the passage of Part H; second, they could modify (in varying degrees) the direction and nature of the previous service delivery system. Fox chose to modify their practices only slightly in order to refine some practices or to comply with federal requirements. Charlie solidly chose modification, including modification as to how the system interacted with the family.

Predictions about which of these processes (or both) will result in successful policies and programs for children and their families in the long term are not possible, but some observations can be made based on the preceding

data. The personnel administering Part H within the division of the lead agency in FOX determined, with approval of the ICC, that the law required minimal changes to its existing system. This approach has resulted in greater consistencies of the interviewees' responses because they understand that they will continue to serve children and families pretty much as they had been doing.

In contrast, Charlie, moving to a more family-focused system, chose an approach that opened up its policy development to the public and to the other agencies in the state. The lead agency provided vehicles (e.g. focus groups to allow parents at the local level to react to policy issues). The biggest changes required by Part H were the identification of family strengths and needs and provision of services to meet the families' needs as they related to the development of their infant or toddler with special needs. Thus, the major difference for states that had been providing early intervention services would be a shift from predominantly child-focused services to a system that was much more responsive to the priorities of the family.

Personnel in both states evidenced concern and respect for families. In Fox, there was consensus based on "This is what we have always done."Personnel and parents in Charlie seemed to feel more responsibility for the development of the mission, direction, and implementation of the program. The strength and the diversity of their opinions about the entitlement issue indicated that many people throughout the state had considered this issue.

The most obvious conclusion that can be drawn from this study is that policy development appears to be much easier if the policies are developed by a single agency and when they impact almost solely on the providers under the direct authority of that single agency. Fox was revising existing practices through rather minor adjustment in attitudes and some practices of existing personnel. In addition, the state was "staying the course" with a predominantly

child-focused program, an approach with a long history in this state. Communication seemed to be expedited under these circumstances, if consistency of opinions can be interpreted as a result of shared communication. Charlie, approaching the development of a family-focused early intervention system as a multi-agency responsibility, presented a system that was much more complex and, at times, more ambiguous.

Whether the state decides to fine-tune its early intervention system with minimal policy changes, or to revise its current practices to a greater degree, the following recommendations emerged from this study:

1. Use the passage of Part H to re-examine the approach the state was using to provide early intervention services. One method is to hire a consultant who is independent of any agency providing early intervention services to compare existing policies and practices with the requirements of the Part H program. Regional focus groups, also led by a consultant who is not considered to be a representative of the early intervention system, can be a means of identifying how parents and/or providers feel about the current system. Input about recommended changes could also be solicited at these meetings. Developing a structure so that providers can channel their feedback to the highest level of policy makers also provides a structure for increased analysis of existing policies programs. Such a structure might include ongoing regional meetings where providers make their views known to one of their colleagues and these regional representatives then meet with the state ICC to relay these perspectives.
2. Inform families, advocates, and providers of the issues and options involved in the provision of early intervention services.

Knowledgeable constituencies might be more involved in the policy development phase. This recommendation requires the commitment of effort and resources if it is to be successful. Newsletters to parents, providers and advocates, workshops targeted at specific audiences, regional conferences, an active public awareness campaign are all ways that should be considered to develop an informed constituency.

3. Provide multiple vehicles for input from the local level to reach the state policy makers. All the methods identified above would serve as useful communication vehicles. Two factors appeared to be necessary for active involvement by constituents. Communication channels must be visible and ongoing and constituents should be informed about the reaction of policy makers to input. Such information could be provided in newsletters or reports giving evidence that suggestions were considered, "because parents overwhelmingly recommended detailed forms for the IFSP...." or "despite some administrators requests that transportation not be an entitled service, legal analysts....."
4. Identify and invest authority in multiple agencies that provide services to this population. This avoids policy development fragmentation and duplication and encourages shared responsibility for the program. A state policy analysis and statewide program review will identify which agencies are providing early intervention services at the current time. Bringing representatives of these agencies together on a regular basis, (e.g. ICC meetings or other multiple-agency council meetings) will facilitate communication and allow the development of the formal and informal processes which are required for effective multi-agency policy development.

5. Involve personnel from all strata of program implementation and policy making: local providers and parents, mid-level management and high level policy makers. Multiple level involvement is critical in the development of policies which are so comprehensive and have such significant impacts on families and programs.

   If high level state policy makers develop policies in isolation, even in a multi-agency effort, such policies are in jeopardy of appropriate implementation. These policies will be provided at the local level and may well be supervised or assisted by mid-level personnel. Parents and children are the consumers of these services and ultimately determine the success of policies. All those impacted by decisions to change or not to modify policies should be involved systematically in the development of policies.

   In addition to the vehicles mentioned above for receiving constituent input additional actions need to take place for thorough involvement. Providers and parents may need to receive training about the Part H requirements and existing state policies. They may need assistance in analyzing existing and proposed policies to identify potential positive and negative impacts. People need to be taught about how to influence successfully policymakers, (e.g. legislators, city council representatives and agency representatives). Agency personnel may need mechanisms to provide anonymous feedback from providers and parents.

The above recommendations require the commitment of resources and effort, both of which might be scarce, in order to achieve involved policy development. These expenditures may well result in appropriate policies which are implemented as designed. Such policy development reflects the spirit of the Part H program and offer promise to develop coordinated, comprehensive, statewide services which maximize the capacities of families and providers.

TABLE OF CONTENT

Page

EXECUTIVE SUMMARY i

INTRODUCTION 1

METHODOLOGY 2
- Site Select 3
- Interviewees 5
- Protocol Development 5
- Structure of the Report 6

RESULTS 8

Family Strengths and Needs
- Identification of Family 8
- Current status of Policy and Practice for ID Families Strength and Needs 10
- Goals for Identification of Family Strengths and Needs 11
- Strategies for Policy Development 12
- Predictions by Interviewees about Policies for Families 14
- Critical Factors Regarding the Development of Policies for Identification of Family Strenghts and Needs 15

Summary of Results (Family Strengths and Needs) 19

ENTITLEMENT ISSUES 20
- Current Status of Policy for Services 22
- Goals for Family Service under the Part H System 22
- Strategies for Policy Development 25
- Prediction by Interviewees - Policies for Family Services 25
- Critical Factors Regarding the Development of Policies for Family Entitlement Services 26
- Summary of Results. - Family Services 27

SERVICE COORDINATION 30
- Current Status of Policies and Practices for Service Coordination 31

Goals for Service Coordination - Part H Sustem..... 32
Strategies for Policy Development..... 35
Predictions by Interviewees about Policies for Service Coordination..... 37
Critical Factors Regarding Identification in the Development of Policies for Service Coordination..... 38

DISCUSSION..... 43
Recommendations for Policy Development..... 46

REFERENCES..... 47

TABLES

PAGE

TABLE 1 - Contextual Variables of Two States..... 4

TABLE 2 - Eight Factors Related to the Phases of Policy Implementation..... 7

TABLE 3 - Policy Development Regarding Identification of Family Strengths and Needs Under the Part H System..... 9

TABLE 4 - Policy Development Regarding Entitlement..... 29

TABLE 5 - Policy Development for Service Coordination..... 42

Introduction

The significant role that families play in the development of children with disabilities has long been noted (Turnbull &Turnbull, 1986). Yet the procedures and policies by which that family role can be maximized have only recently gained the sustained attention of the professional community (Dunst & Trivette, 1990; Gallagher & Vietze, 1986). The emergence of legislation such as the Infant and Toddler Program, Part H of the 1986 Amendments to the Education for All Handicapped Children Act, P.L. 99-457 (now reauthorized as the Individuals with Disabilities Education Act), which requires that early intervention programs consider the needs and priorities of parents as well as those of the infant or toddler, has furthered an increased attention to the family.

Robert Silverstein, Staff Director and Chief Counsel of the Senate Subcommittee on Disability Policies, identified the critical role of families in the Part H legislation:

> Congress wanted the language of the bill to reflect our utmost respect for the family. The word "family" must appear ten or fifteen times through the legislation; this was intentional. Congress was trying to say, Do not have professionals come into a family situation and assume that the mom and dad don't know anything. Respect the family. The language in the legislation, which talks about strengths as well as needs, is an attempt to recognize and provide respect for the family .... There is nothing more central to this legislation than respect for the family (NCCIP, 1989).

The passage of P.L. 99-457 is an illustration of the use of legislation to produce reform. One of the clear dimensions of that reform is represented in the mandated relationship between professionals and the family. As Dokecki and Heflinger (1988)

pointed out, "There have been few watershed events in the social ecology of families of children with handicapping conditions, but P.L. 94-142, the Education of the Handicapped Act, surely was one. Many of us hope and expect that P.L. 99-457, the Education of the Handicapped Act Amendments of 1986, is another watershed, especially for young children."

The intent of this law is to strengthen the family's role in planning and providing for their own child and is manifested in part in two major provisions. These are the development of an Individualized Family Service Plan (IFSP), in which the needs and strengths of families as well as children may be identified and addressed, and the service coordination (case manager) requirements, which provide a single communication and coordination point for the family members as they interact with the professionals providing services to their child.

This study, conducted by the Carolina Policy Studies Project (CPSP), identifies the critical factors affecting policy development in two states as they begin to develop policies for the Infant and Toddler Program (Part H). The study has focused on the strategies used to develop policies in areas that most directly impact on families of young children with developmental delay and disabilities: the IFSP, the identification of families' strengths and needs, and service coordination. Such information may assist other states in developing policies which support and enhance family functioning.

Methodology

Gallagher (1990) has proposed that there are three broad stages in the development of policies: development, approval, and application. The initial stage of policy development was selected because of the recency of the passage of this federal mandate, the Infant and Toddler Program. The law was passed in 1986 but the federal

regulations were not promulgated until June, 1989. Site visits were made in the early spring of 1990. Prior to the passage of P.L. 99-457, the two states chosen for this study had developed unique and nationally recognized approaches to early intervention. The changes required by the federal law, however, meant that new policies had to be developed and/or existing policies revised. Therefore, studying policy development activities was appropriate to the timing of the first phase of this study.

Qualitative methods were used to gather and analyze the data on which this report is based because these methods facilitate the study of selected issues in depth and detail (Rutman, 1984). Of the qualitative methods available, the case study was selected as the mechanism to structure this study. In order to identify the decision processes used by states, information about how these policies are being developed had to be gathered. As Yin (1984) explained, when a "how or why question is being asked about a contemporary set of events, over which the investigator has no control" the case study has "a distinct advantage" (p. 20). Data were gathered through structured on-site interviews.

Site Selection

Two states were selected to serve as contrasting cases for this study. These states will be referred to in this report as"Fox" and "Charlie." These terms are drawn fromt he international alphabet (able, Baker, Charlie, Dog, Easy, Fox, etc). In one state, Fox, the implementation of the early intervention system is and has been primarily an effort carried out by a single lead agency. In the second state, Charlie, efforts are and have been guided by a philosophy and practice of shared interagency responsibilities. Table 1 summarizes the structure, history, climite, problems population and approaches of these two states, as determined by the CPSP investigators.

Table 1

Contextual Variables of Two States

Variable	Fox	Charlie
Degree of System Change Desired	minimal	moderate
Structure	single agency	interagency
History	substantial	substantial
Political Climate	poor	medium
Wealth[1]	first quartile	last quartile
Human Service Problems[2]	third quartile	last quartile
Homogeneity of Population[3]	high	high

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[1] Wealth is the median family income. Source: Statistical Abstract of the United States. 104th Edition (1984). U.S. Bureau of the Census.

[2] Human service problems are based on the average of state ranks on 3 variables: percentage of high school dropouts, percentage of births that are low birthweight, and percentage of infants born to teenage mothers.

[3] Homogeneity of population: High = 0 - 6% minority. Source: Statistical Abstract of the United States, 104th edition (1984). U.S. Bureau of the Census.

Source: Brizius & Foster (1990). States in Profile: The State Policy Reference Book. McConnelsburg, PA: Author.

Interviewees

The director of the Part H program within the lead agency in each state was sent a list of the types of people that the investigator wanted to interview. The director was requested to identify individuals who provided the type of representation described by the investigator. For this study of family policies the list of representatives included: parent members of the ICC and from the state parent and information center, members of the ICC involved with decision-making about the topics under study, agency personnel involved in making decisions about or implementing these decisions, and providers of early intervention services.

Six people were interviewed in state Fox. Each interview lasted from two to three hours. Interviewees included three state agency representatives, two parents who were members of the ICC, and a director of an early intervention program that was serving as a pilot site for Part H activities. The director of the lead agency was also interviewed briefly to provide perspectives about the climate and priorities regarding policy development in the state.

In state Charlie, data were collected by interviewing 14 people, including representatives from several state agencies, three parents, and service providers. Most interviews lasted from 1.5 to 2 hours. A telephone interview was held, in addition, with a consultant who had conducted local focus groups with parents throughout the state.

Protocol Development

Few existing written policies meeting the requirements for the Part H program were available for analysis, so attention was devoted to the development of the interview protocol. Initial questions addressed the current status of policies in the state. Subsequent questions were structured to gather data related to the initial stage

of policy development. Interviewees were asked about their goals for the Part H system in three specific areas of policies. Questions such as, "What steps are being taken?" or "What actions are occurring in the state that make it likely that this goal will occur?" resulted in the identification of potential strategies for the development of policies. "How likely is it that this policy/strategy will happen?" served to focus the interviewee on predicting outcomes.

Site visits lasting three to five days were made to each of the states to collect data. State reports were written and sent to the Part H coordinators to verify the accuracy of the information recorded.

Structure of the Report

Identification of the current status of state policies is useful in learning what activities were occurring prior to, and very shortly after, the passage of Part H legislation. Goals mentioned by the interviewees for the Part H program are reported. Projected strategies that were reported or observed by the investigator to develop policies in these areas are identified. Predictions based on likelihood statements about the accomplishment of these goals were offered by the interviewees.

Once these data are presented, the report identifies the critical factors thought by CPSP personnel as having a significant positive impact on the development of policies in each of the states. The CPSP has identified eight factors that are associated with policy development. These factors are: history, political climate, available resources, existing policies, key people, policy development process, state government structure, and shared vision. These critical factors are defined in Table 2 (Harbin, G., Eckland, J., Gallagher, J., Clifford, R., & Place, P., 1991, p. 7). When there were significant characteristics of a state that were having a negative effect on the development of policies, these are presented in the Current Status, Goals, Strategies, and/or Discussion sections, as relevant.

Table 2

Eight Factors Related to the Phases of Policy Implementation

History	A state's past record of service provision and coordination for young children with special needs.
Political Climate	Current sentiment in the state, especially among key policy makers, regarding the need for child-related programs and policies.
Available Resources	Availability of fiscal resources or programs for handicapped infants and toddlers. Availability of trained personnel and/or personnel preparation programs in the state to meet service demands.
Existing Policies	The comparability and compatibility of existing policy statements (e.g., statutes, standards, guidelines) with policy required by Part H of P.L. 99-457.
Key People	State government officials, agency staffs, and advocacy groups who play a role in Part H policy development and application.
Policy Development Processes	Formal and informal procedures used to develop and obtain approval of policy related to Part H.
State Government Structure	Location and authority of Part H related to the decision-making points in state government.
Shared Vision	Clear articulation of conceptualization of a coordinated service delivery system for Part H by more than one power source.

Source: (Harbin, G., Eckland, J., Gallagher, J., Clifford, R., & Place, P., 1991, p. 7)

Note: Those factors that are applicable appear in each of the succeeding sections -- Family Strengths and Needs, Entitlement Issues, and Service Coordination

Results

Family Strengths and Needs

Emerging best practice in the field of early intervention has progressed to the point where family members have a vital role in identifying their family's needs and strengths. This is a fundamental change from the traditional approach of relying on professionals to assess families' strengths and needs. Bailey (1989) explained the traditional approach and the attempt to change to a more family centered approach:

> Traditionally, families' priorities for themselves and their children were not identified until after the assessment was completed. Most often, the same assessment process, instruments, and procedures were used for all children and families, with relatively minor adaptations ...Family questions or concerns typically played little part in shaping the assessment so that the process and its findings often met the needs of the staff and program, rather than the needs of the family ...Many early intervention programs, however, are changing this practice. Beginning with their first contacts with a family and continuing throughout assessment outcome development and IFSP evaluation, a family is asked to share its agenda for the child and family ... that will ultimately determine the IFSP outcomes. (Bailey, in Hanft, 1989, p. 3-39).

These changes in what is now considered "best practice" are reflected in Part H in the requirements that a family be able to identify its strengths and needs as a basis for the IFSP. This study investigated the changes that two states were undergoing as a response to the emerging best practice and federal requirements.- Table 3, summarizes the data obtained from these two states.

Table 3

Policy Development Regarding Identification of Family Strengths & Needs Under the Part H System

Fox	Charlie
Goals	
• Emphasize family role • Increase informality • Write down all needs (even if not entitlement services)	• Make Policies consistent among all agenc • Minimize duplication of services • Systematize procedure • Keep Cross agency training together
Strategies	
•Pilot projects	• Consultant review policies prior to 99-457 • Consultant conducting regioal focus group
Predictions	
• Mixed opinions about possibility of goals being met, based on: some providers will change, some won't. Philosophy of program director positive. High visibility of issue throughout state as incentive to change.	• Overall positive opinions about possibility of goals being met, based on: Desire "to stop bugging families" consisten across agencies. Several state initiatives as successful precedents.
Critical Factors	
• History • Resources • Existing Policies • Policy Development Processes • Structure • Vision	• History • Resources • Existing Policies • Policy Development Processes • Vision

Current Status of Policy and Practice for Identifying Families' Strengths and Needs

The current policy in state Fox, the primarily single agency state, was that the projects that carry out the early intervention activities in the state had the responsibility for the identification of family needs and strengths. The state lead agency had a direct impact on this identification process because all the projects were run under the authority of the lead agency. Other agencies in this state conducted activities that were similar to those performed under the auspices of the lead agency, but these were not considered early intervention activities and were not a part of the system used for the implementation of Part H. State agency personnel said discussions had occurred about attempting to influence other departments' policies and practices as they performed activities comparable to early intervention services. The decision had been made that the lead agency could only influence those activities over which it had direct authority.

Some providers and agency personnel indicated that, in the current early intervention system, individualized program plans could include goals for the family as related to the development of the child with special needs. These goals for the family were based on information collected using a combination of formal and informal processes to identify the needs of families. These data collection strategies varied across programs. As reported, goals were often suggested by the practitioner rather than by the family. These goals often had to do with changes the family needed to make in order to carry out the early intervention regime designed by the providers for the child (i.e., home therapies).

Specific policies for Part H implementation were being discussed at the time of the interviews in Charlie. There were existing policies developed prior to passage of P.L. 99-457 about the scope and purpose of family assessment in this interagency

state. During these discussions, the interviewees in Charlie expressed more questions and concerns about family assessment than in Fox. Many of those interviewed suggested that the current policies were too vague and that there was a need to develop more specific standards. As one interviewee stated, "We need to figure out what family assessment means and what it should include. How far should we intrude into the family system? There needs to be training to raise consciousness on the part of everyone to deal with the issues of intrusiveness and the goal of family assessment."

Multiple agencies in Charlie were identified as having a role in the identification of family strengths and needs in the implementation of the Part H program. Some examples of the multiple activities are provided here to demonstrate the level of activity. While the level is high, all families were not given similar services in all parts of the state. Public health nurses provided an initial assessment for many families of newborns. A SPRANS grant was used to pilot guidelines for practitioners to use to determine when to refer a family for further evaluation. One of the agencies offering service coordination services completed family assessments. Early intervention program staff sometimes identified and tried to address family needs.

Some interviewees reported that one of the problems with having so many people doing family assessments was that the services were sometimes fragmented and lacked coordination. Another concern was that some families were overly assessed while some received a minimal assessment of their needs because the services were not there if certain needs had been identified during the assessment.

Goals for Identification of Family Strengths and Needs under the Part H System

The goals of the process for the identification of families' strengths and needs seemed to be changing in Fox. One of the themes that emerged from all interviews in

Fox was that families must now have more of a role in deciding their needs and goals. As stated by one, "You won't see goals written by staff and they go out and get the parent to sign the plan." Additional policy goals mentioned by all interviewees were to make the process more informal. A final policy goal offered by each person interviewed was the need to write down all the services that a family needs, even if there were no services currently available. Concern was expressed about the negative consequences of this approach, but the overall good of identifying gaps in service seemed of paramount importance. Also, some people stated that the service coordinator should be responsible for attempting to identify resources to meet these unmet needs.

The interviewees in Charlie emphasized the need for policies that transcended agencies and for training that crossed the boundaries of agencies and disciplines. There was a common thread among the interviewees with regard to a desire to develop policies that maximized the use of all staff. "We need to define what is family assessment and what it includes. There are some activities that anyone can do, whereas not any one person can do everything."

A second, equally strong, theme was the need to minimize duplication and intrusion, "so that six people don't go into the home and ask the same ten questions." Concern was expressed that families should be the ones to say how much disclosure is helpful and how much is too much. Opinions were offered about the need to systematize the procedure for acquiring information from and about the family. Interviewees also expressed the need to use common consent forms across agencies and to share information across agencies. Very often, interviewees suggested cross agency and cross discipline training.

Strategies for Policy Development

In order to increase providers' skills and activities in identifying families' strengths and needs, Fox has funded pilot sites to identify the strengths and needs of

families. The pilot sites have been trying new strategies to make the process less formal and to give parents more authority to identify their own strengths and needs. These pilot sites are assisted by an outside consultant who has presented recommendations directly to the ICC. There is active communication between the pilot sites and the staff at the lead agency.

In Charlie, there was a great deal of talk among those on the ICC, in the lead agency, and at the local level, about the processes by which a family's needs and strengths should be identified. These talks focused on the goals delineated in the previous section. This type of informal networking can be a powerful policy development . One interviewee expressed concern that the ICC was not as aware of the ramifications of policies about family assessments as they should be: "The ICC ...doesn't realize how potentially damaging this can be ... they don't realize what the negative impacts can be." This person was concerned that assessing families' needs might lead the service provider to inquire into areas of the family that were too private or otherwise not appropriate subjects for the early intervention program staff.

At the time of the site visit, consultant was reviewing existing policies written prior to P.L. 99-457 to determine if these were appropriate for the newly mandated federal Part H program. Another consultant had been hired to conduct focus groups at the local level in different regions throughout Charlie to solicit parents' input about the early intervention system. This was consistent with the goal of allowing families to have a significant role in determining the nature of early intervention policies. The consultant stated that concern about the identification of family strengths and needs emerged as a significant topic in these focus groups. At the time of the visit, these data were, being collated and analyzed by the consultant and a report was expected soon. No interviewee reported formal activity about family assessments on the part of the ICC or lead agency, except for heightened awareness about this issue.

Predictions by Interviewees about Policies for Families

The interviewees in Fox expressed mixed opinions about the success of revising the existing system to be more family focused. As one predicted, "About a third of the early intervention programs are gung-ho and excited about the change. One third are on the way, but a few steps behind. The remaining one-third just don't get it yet -- they say, 'OK, we'll just add in some goals for the family".

Others in this state reported that change depended on changing perceptions. "It's all in establishing the context. When you look at having a child with a disability as pathological, you try to figure out what they [the family] need and then you help them. Instead, you can assume they are fine, they're already competent and [we] are consultants coming in to assist them. "These changes in perceptions were predicted to take some toll on personnel: "In the past, professionals have related to families as the experts who perform magic. We have already lost staff who said they wanted to work with babies, not families -- I wasn't trained to be a social worker".

Optimism was expressed by some about the single lead agency in Fox and its ability to change perceptions. One of the factors cited was that the philosophy of the new program director was oriented towards improving services to families. A second factor was that this topic had high visibility throughout the state.

In Charlie, one of the major reasons cited for developing a system that crosses agencies and disciplines was the desire by many parties "to stop bugging families." Many interviewees stated that professionals really care about families and want to provide help with a minimum of intrusion. Several state initiatives were also cited as precedents that support the idea that this type of cross-agency cooperation might occur: one initiative addressed interagency tracking and the other initiative involved developing a common consent form across agencies for the juveniles in correctional facilities. If cross-agency cooperation could be done with one population, some

speculated, the success could be a model for service to infants and toddlers and their families. One drawback might be the lack of personnel to carry out these cross agency activities.

Critical Factors Regarding the Development of Policies for the Identification of Family Strengths and Needs

Based on the interviews, the following critical factors were determined by the investigator to be positively influencing the development of policies for the identification of the strengths and needs of families in Fox, the single agency state, and Charlie, the interagency state: history, resources, exisiting policies, policy development processes, structure (for Fox), and Shared Vision. While both of the states possessed some of the same broad factors, the nature of the specific characteristics were considerably different.

History -- Fox. Staff indicated that they felt they had been meeting the law's requirements in full, or in part, because some programs had been identifying family strengths and needs already.

History -- Charlie. The identification of a family's strengths and needs had been occurring in a variety of ways for some time. Various agencies had policies in place. Thus, there were substantial activities and policies to serve as an experimental data base for the development of policies for the Part H system.

Resources -- Fox. An extensive network of existing early intervention staff and programs under the direct authority of the lead agency allowed Fox, the single agency state, to experiment with changes in program policies and procedures by providing grants for very specific purposes.

Resources -- Charlie. There was quite a lot of activity in Charlie related to the assessment of families' needs and strengths. There were existing policies in various agencies and departments, mechanisms to identify family strengths and needs had

been in place for some time, and there were some experienced personnel. These resources could be used as catalysts for the early intervention program.

Existing Policies -- Fox. The early intervention system already had allowed each program to identify family strengths and needs as they related to the developmental needs of the child. If they need to modify their policies, the indication is that they will revise these existing policies rather than changing to a totally new paradigm (i.e., identifying the needs of family members that are not directly related to the needs of the infant or toddler).

Existing Policies -- Charlie. This state had written standards to provide guidance for the identification of a family's strengths and needs. The standards were being reviewed to determine their applicability to the families of infants and toddlers. The existing standards appeared to provide some, but perhaps not sufficient, guidance. The standards appeared to indicate that fairly global information may be collected about families. The vagueness seemed to leave many people with serious questions about the implementation of this facet of the early intervention program.

Because this topic had been the subject of many discussions and because there was fairly extensive experience to serve as a data source, everyone interviewed in Charlie had some serious questions about the policy regarding assessment of families. Interviewees seemed to suggest that some guidance should be provided to structure the assessment of families.

All of the following questions emerged from more than one interview. (What information is relevant and who is best suited to collect this information?). Should these decisions be made on a case-by-case basis, at the local/regional level, or by the ICC? In what manner will parents' rights to privacy be protected? How will all target personnel be informed about these policies, i.e., what training and technical assistance will be provided to make sure that the variety of people conducting family assessments are aware of these principles? In what fashion will the family

assessment process be monitored and supervised to ensure that those conducting the assessments operationalize these policies and principles?

Structure -- Fox. The pilot early intervention programs were in close contact with the lead agency, so information moved in both directions. The lead agency was very aware of what was going on "in the field" and watched carefully the effects of the experimental activities of the pilot projects. This communication allowed the lead agency to share this information with the relevant committee of the ICC. Therefore, those who would be making the ultimate decisions regarding these policies were kept informed of the pilot findings.

Structure -- Charlie. Given the multi-agency leadership for developing guidelines for the Part H program, constituents from each of the agencies currently conducting assessments of families will be represented as decisions are made about this aspect of the program.

Policy Development Processes -- Fox. The use of an outside consultant in Fox, combined with extensive pilot work, was providing the ICC and the lead agency with data. These data could serve as a base to revise the Part H policies for the identification of a family's strengths and needs, if such modification of existing policy was determined to be necessary or desirable.

Policy Development Processes -- Charlie. Extensive activities across agencies seemed to have encouraged formal and informal discussions about the identification of families' strengths and needs. Once recommendations from the consultants were received, the ICC was expected to consider development of a formal policy.

Shared Vision -- Fox. A clearly articulated vision of identifying and meeting families' strengths and needs was espoused by state agency personnel in Fox, based on what was already allowed and encouraged by the lead agency. The needs and strengths of the family that were appropriate to be addressed by the early intervention staff were those that were tied directly to the needs of the infant or toddler. No family

need that did not directly impact on the development of the infant or toddler was appropriate for the early intervention program (e.g., an allowable family objective would be to assist the family to carry out the child's physical therapy program at home). There was consensus that the change needed was that the identification of needs and strengths must be more informal and more driven by the family.

There was also consensus among the interviewees that the family be the one to set goals for the family. Interviewees said that not all providers shared the goal of including families' needs in the early intervention service delivery system. Each person interviewed agreed that all needs identified by the family be listed on the IFSP and that the early intervention system's responsibility was to be knowledgeable about and to assist the parents in identifying the services to meet these needs. However, they felt families were not entitled to receive these services form the early intervention system.

Shared Vision -- Charlie. One of the trends that emerged from interviews was the commitment of all key players, agency personnel, providers, consumers, and advocates to develop policies and programs that support families to the extent that is needed by each family. There were many reports of statewide activities to develop or modify existing services so that they are truly family-centered. Interviewees were consistent in asserting that the policies they want for the identification of a family's strengths and needs should help families and minimize intrusion.

There was wide-spread support among those interviewed for developing a uniform process of identifying a family's strengths and needs that could be used by any professional working with the family. Most people recommended that a variety of professionals be trained to do this assessment. Many incentives for this approach were proffered by a variety of interviewees. Perhaps most significant was the realization that this approach is already being implemented across a variety of agencies with a different population in the state.

Summary of Results

Fox used an outside consultant and pilot projects to attempt to change the philosophical approach that early intervention staff, under the authority of the lead agency, currently used to identify the strengths and needs of families. State agency representatives hoped that the early intervention programs would move from the philosophy that parents were targets of intervention to a realization that parents were equal partners in decision-making about early intervention. This change was expected to be difficult for staff who were used to, or preferred, operating under the traditional clinical philosophy of treating the child as a patient or client and parents as passive recipients of services.

There may be changes and variation in the identification of families' strengths and needs at the local level as a result of P.L. 99-457, but such change would not be likely to be driven by changes in policy at the state level. Rather, this state seems to be focusing more on "attitude adjustment" of the providers about how they perceive and interact with parents. This refinement of attitudes was expected to require only minimal service system revision, such as changes in in-service topics.

At the time of the site visit to Charlie, people from a multitude of agencies conducted activities to identify a family's strengths and needs. An unintended result of having multiple professionals conducting these types of activities was that the processes of identifying family strengths and needs sometimes were fragmented or duplicated. The goal espoused by the great majority of interviewees was to conduct the identification of family strengths and needs so that some families were not inundated with people inquiring into their family issues whereas other families did not receive appropriate assistance.

Interviewees in Charlie were unanimous in their recommendation for state level guidance, including a call for consistency of policies and practices across all agencies throughout the state. What made this finding somewhat unexpected is that this state

has a strong history of local autonomy. Consistency in the fairness with which families were treated throughout the state appeared to outweigh the locals' desire for primary decision-making.

Some people reported that Charlie's ICC was not aware of the potentially negative effects of the process of identifying a family's strengths and needs. They expressed concern about violating the family's rights to privacy. Concern was also raised about the possibility of usurping the traditional independence of the family by making them too dependent on the formal system if the professionals became involved in decisions made about family matters. The fact that local providers and parents expressed concerns at this level of sophistication reveals that the philosophy underlying and the practices of identifying family strengths and needs has been a topic receiving serious exposure throughout the state. An interesting findings was that none of the specific questions brought up by multiple interviewees in Charlie were addressed by Fox's interviewees. The questions from Charlie's interviewees were at a more abstract level, perhaps because the personnel in Charlie have had discussions over a longer period about these policies than has yet occurred in Fox.

Little systematic activity among key state policy makers seemed to be addressed to this topic area at the time of the site visit. This lack of attention may be because of timing: a consultant had been hired just prior to the site visit to review existing policies while, simultaneously, grass roots activities were being undertaken to provide information about parent perceptions on a variety of policy issues.

Entitlement Issues

Federal law can require that a state provide a system of services that is available to those eligible (i. e., mandate that such a system be established), in order for the state to receive some incentive or to avoid some sanction from the federal government. In such situations, an eligible person is eligible to receive the services

available under this law if state and federal resources are available to provide such needed services.

Alternatively, a law can require states to make available to each and every eligible recipient the services described in the law. An example of this type of entitlement program is the special education statute for school age students. All children who are disabled and in need of special education have a right to special education and related services they need, as indicated by each student's Individualized Education Plan (IEP).The Part H program is an entitlement program; all eligible infants and toddlers and their families must be provided all services needed by the infant or toddler or family as they relate to the development of the eligible infant or toddler. This right to needed services is not limited by the availability of federal, state, or local resources.

The Part H statute does not make explicit the services to which the infant and toddler and their families are entitled. This is to be determined on an individual basis and is to be described in each IFSP that is developed for each eligible infant and toddler. Given that family services, as required by Part H, are somewhat new services under the 1986 amendments to the Education of All Handicapped Children Act, state policy makers are uncertain about which services a family is entitled to under this program. Most states want to assist families to obtain all the services that the family needs but, in reality, the services required under the Part H program must be delimited in some way because of the scarcity of resources at the state and local levels and the minimal funding provided at the federal level (see Clifford, 1991, for a discussion about finance issues).

How do states determine which services families are entitled to receive? What are the services that the service coordinator will attempt to assist the family to receive, but to which the family is not entitled under Part H? Will states develop different family service patterns based on idiosyncratic aspects of the state, or will states offer the

same types of services as entitlements? The following case study data document the issues addressed by two states.

Current Status of Policy for Services

For over 10 years, the lead agency in Fox has had a mandate to provide early intervention services to infants and toddlers with handicaps. While there is this mandate, there is no entitlement. Therefore, if a program -- or individual case load-- is full, a child will be placed on a waiting list until the needed service can be provided. Also, the early intervention system as a single agency system does not rely heavily on other agencies to provide services. The traditional service delivery system has primarily provided services addressed directly to the child. The passage of Part H has motivated some analysis of the extent to which the state's current policies and procedures comply with the federal requirements to provide services needed, but such analysis has been rather minimal.

Policies regarding the IFSP often evolve into discussions about what services are entitlement services and which are desirable but to which the family is not entitled. Many interviewees reported that persons and agencies in Charlie have discussed this issue in depth over quite a period of time. These deliberations have resulted in the development of written draft policies for a continuum of services ranging from services that are a fundamental right of all families in the state, to entitlement services for children who meet Part H eligibility requirements, through services that are desirable but not necessarily entitled services.

Goals for Family Services under the Part H system

The interviewer wished to get some more specific information about the entitled services. In order to obtain such information, a vignette of a family with a newborn was presented to the interviewee, who was asked if the services requested by the family

were services to which the family was entitled. The vignette presented to the interviewees of each state follows:

> A mother in a rural area of your state goes into delivery very early in her pregnancy and complications develop with the infant after her birth. The baby is air-evacuated to the nearest Neonatal Intensive Care Unit (NICU), which is 600 miles away. Since the baby meets the eligibility requirements for the early intervention system, a service coordinator is assigned and contacts the family, explaining that the program is for early intervention which includes services to enhance the capacity of the family to meet the special needs of their child. He asks the family what they need. The family members immediately say that they want the mom to be able to go down and see the baby. They don't have a car that could make the trip and they don't have the money to be able to go. "My baby needs to be held by her mama. That's what she needs to get well and grow up strong." Is the mother entitled to transportation to the NICU and for accommodations so she can spend the night and have the most time possible with her newborn?

The interviewees in Fox had very clear goals and expectations about the services to which families were entitled under Part H. In this state, the services to which a family was entitled were carefully restricted by the interviewees. The services to which a family was entitled were: identification of strengths and needs, service coordination, and those services that focus on the developmental needs of the infant or toddler.

Every interviewee in this single agency state was in agreement that the transportation and lodging requested in the vignette were <u>not</u> services to which the family was entitled. Most interviewees did go on to say that the Part H system should list these needed services on the IFSP and assist the family in trying to find resources

to meet this need. One comment exemplified those of the others: "... but there should be vigorous assistance to .ry and find these services for the family. I'd be seriously concerned if a program didn't ask questions about this and go to measures to locate these services."

Policy statements in Charlie described a goal for a continuum of services that should be provided to families. The IFSP team had varying responsibilities for assuring that services are provided to families. The draft description of the levels of services begins with level one, which are the "fundamental rights that apply to all human beings within our society. These may be available to families and young children through personal resources, public and private programs and social service support systems" (draft state document on levels of services). Another level in this continuum describes the types of services that the family is entitled to under Part H. This draft continuum was the result of several years of activity in Charlie, including discussions among high level policymakers based on in part systematically solicited from manager, providers and paents.

In Charlie, where so much time has been spent delineating levels of services and rights to entitlement, there was a much greater diversity of opinion about this vignette. The majority of respondents said the family was entitled to the services requested in the vignette. The responses tended to be opposite extremes, either absolutely "Yes" or absolutely "No." Two examples clarify these polar positions. On the affirmative side was this comment: "Yes. This needs to be ensured. Families are entitled to whatever support services are necessary to keep them functioning as typically as possible. Siblings are also entitled to some services. You are entitled to whatever you need to minimize the stress on your family e.g., care of the siblings while the mom is gone to visit the NICU, sibling counseling and support, and whatever else is required."

The view that these services were not an entitlement was expressed by several people. As one person explained, "No, the family is not entitled to these services. If you have to make a choice between a warm fuzzy and hard core services, then you go for the second choice. It comes down to a problem of giving a lot to a few or a little, but essential, to many." Differences of opinions could not be traced to representation of constituency. Some parents and agency people said, Yes, and some of each held the opposing opinion.

Strategies for Policy Development

In Fox, the law was not seen by state agency personnel or others interviewed as adding any additional responsibilities to the state early intervention system that was already in effect. Therefore, no changes were recommended in the services provided.

In Charlie, there has been wide-spread discussion about the services to which families are entitled and an elaborate matrix has been developed to convey this information. Plans are to pilot this matrix and then determine state policy based on the findings of the pilot.

Predictions by Interviewees - Policies for Family Services

No predictions were offered by people in Fox about the service delivery system, since no changes were being proposed. In Charlie, there was optimism that the services defined as entitlement would meet the needs of families as well as the family's infant or toddler. Most relied on the piloting of the service matrix to provide input about the range of entitlement services needed by the family.

Critical Factors Regarding The Development of Policies for Family Entitlement Services

The critical factors that may be influencing the development of policies, (i.e. history, climate (Charlie), existing plicies (Charlie) and key people (Charlie) are summarized below:

History -- Fox. There was an established early intervention system in the state. The lead agency implemented these programs. There was very little disagreement about the services to that a family was entitled to receive under the early intervention system. No plans were identified to seriously modify the current delivery of services to families and no major changes were expected, except that more families were expected to become eligible for services.

History -- Charlie. Many agencies in Charlie had a history of providing a variety of services. Whatever modifications resulted from Part H were expected to build upon this foundation, expanding the types of services to be provided and those eligible for the services.

Climate -- Charlie. Even given the shortage of resources, there is an atmosphere of "doing what needs to be done to assist families." There is a sense of resourcefulness and creativity which enabled the interviewees to appear positive and confident despite obvious challenges. An often quoted statement was "we take care of our own".

Existing Policies -- Charlie. There were well described levels of services providing guidelines delineating which services were entitlement services and which were not. Even though these policies have been widely disseminated, there were divergent opinions in reaction to the vignette, indicating that there was some disagreement about whether a given service would be an entitlement or a desirable

outcome. These draft policies had served as a basis for extensive discussions about Part H policies.

Key People -- Charlie. Key people in this state were very involved in the discussions about entitlement services. This subject had the direct attention of the highest state agency personnel as well as key constituencies. These people were responding to the passage of Part H as an opportunity to review and refine the policies they had been developing.

Summary of Results - Family Services.

Differences in the consistency regarding entitlement among those interviewed in Fox, as compared to those interviewed in Charlie, was an interesting finding. While Fox interviewees showed cohesion on the question of entitled services, the Charlie interviewees varied greatly on this topic. The ICC providers, parents, and agency personnel in Charlie had engaged in frequent discussions with each other about the topic of "entitlement". This state had developed written policies about the services to which a family was entitled. Yet the interviewees in Charlie expressed opinions that were polar opposites about the services to which a family was entitled in the vignette.

Meanwhile, in Fox, a state that appeared to have had little systematic discussion about the area of entitlement, the opinions of the interviewees showed remarkable consistency. This consistency may be a result of the structure for the planning and implementation for Part H. The early intervention program is a relatively straightforward system carried out primarily through a single agency, and minor changes in practices were expected as a result of the passage of Part H. Perhaps this approach facilitates understanding of policies between those at the policy planning level and those providing and receiving the services.

A second possibility is that selection bias may have resulted in this consistency because all interviewees were selected by the lead agency. However, no significant

opposition to the lead agency's plans appeared in almost a week of interviews in various parts of the state. The most likely reason for such consistency is that this state has a long history of providing services utilizing this single agency approach, and there did not seem to be any desire to change this system very much as a result of Part H.

The early intervention system in Charlie was much more complex, involving many more agencies and constituencies. Furthermore, Charlie was entertaining the concept that the changes brought about as a result of Part H would lead to moderate system's change, not refinement of existing policies and practices. CHARLIE'S planning focus involved far more constituencies. Concomitantly, interviewees displayed far greater diversity of opinions about entitlement. The conflicting opinions were not accounted for by any one constituency (i.e., consistency was not found among agency personnel or among parents). Agency personnel differed with other agency personnel, parents differed with parents, etc. Many people had been involved in active dialogue about this important issue and had developed their own opinions about what families should be entitled to under this system.

At this initial planning stage, this participatory policy development had not resulted in consensus. Perhaps experience in providing these newer, family-focused services over time might result in more consistency across constituencies. If such consistency is not achieved, a system of disparate service delivery might result. Such a situation might result in inequity and confusion about services. As an example, a family living in one part of the state might be told that they are "entitled" to a given service; if that family they moved to another part of the state, they might be told something very different.

Table 4

Policy Development Regarding Entitlement

Fox	Charlie
Goals	
• Consistent responses across all interviewees.	• Inconsistent responses.
• Restrict family services to: identification of strengths and needs, case management, and those services that focus on infant or toddler.	• Restrict services entitled under 99-457 but express assumption that some basic health and wellness services are "fundamental rights" of families.
Strategies	
• No change in current service delivery.	• Widespread discussion about needed changes. • Draft matrix with levels of services being piloted.
Predictions	
• No significant change will occur.	• Mixed responses and cautious optimism by majority: families will systematically be entitled to more comprehensive services.
Critical Factors	
• History	• History • Climate • Existing Policies • Key People

Service Coordination

The Part H program requires that states offer families the option of identifying the families' strengths and needs. The service coordinator is charged with assisting families in meeting these needs. When professionals become involved in such intimate decision-making activities with a family, the chance of negative interactions increases. For example, a service coordinator might see that a family needs to be consistent in their discipline for the child with special needs and might recommend that the parents attend a parenting class. He convinces the parents to agree to let him refer them to a clinician and sets up the appointment but the parents fail to show. The service coordinator begins to think of the parents as"non-compliant" and the family begins to regard the service coordinator as intrusive and dogmatic. The relationship could deteriorate to the point of ineffectual service coordination. Dunst, Trivette and Deal, have articulated an approach to interacting with families in ways that empower families. However, in Enabling and Empowering Families they relate that:

> The fact of the matter is many professionals have considerable difficulty with the position we take in this book. How are we to resolve the conflict between what families and professionals believe ought to be done when there is a lack of consensus between the respective parties? (Dunst, Trivette, & Deal, 1988).

Perhaps the timing of identifying needs is as important as the process used to identify these needs. Maybe if the service coordinator cited above had waited until the parents had a solid relationship with him or until the parents brought up the need to improve disciplinary consistency, the results would have been much more positive. Service coordination decisions will serve as an anchor for families who interact with the early intervention system and so are vital to the success of this program.

The service coordinator will have the responsibility for integrating the various professional services delivered to the family. But how does the service coordinator fit into the state system of service delivery? How will the service coordinator be selected and how qualified will this person be? How ill multiple service coordinators interact witht he family? Policies about service coordination are crucial in determining what impact state policies might have on the lives of individual families. This report provides information to contrast two states' approaches to the development of Part H policies. Table 5 provides a summary of these findings.

Current Status of Policies and Practices for Service Coordination

For all infants and toddlers receiving early intervention services in Fox, staff who provide these services at the program level are assumed to be service coordinators. Service coordination services were one of the early intervention services that all early interventionists were expected to provide as part of their routine responsibilities. At the state level, there is a sub-committee of the ICC that is reviewing policies for the Part H system of service coordination. This sub-committee began its work in the summer of 1988.

This state also has a division within the same agency that is the Part H lead agency that has a long history of providing service coordination to certain targeted populations, some of whom may be infants and toddlers or families eligible under the Part H program. This service coordination system has developed an extensive network of skilled case managers (an apparently successful model), well developed training materials, and a structure within the agency for management of the complex services provided. The model is predicated upon tiers of service coordination services. Tier I would require routine coordination and advocacy services and Tier III would provide intensive and/or complex assistance. Tier II services fell in between these levels.

Charlie started working on policies for service coordination in 1985, predating the passage of P.L. 99-457. These policies were being reviewed after passage of that Act. A statement from a subcommittee of the ICC defined service coordination to include: intake/assessment, development of a client-centered plan, evaluation of the effectiveness of the services delivered and reassessment of the client's needs on a regularly scheduled basis. Many agencies and providers deliver some level and type of service coordination services to various constituencies in the state, some of whom are also eligible under the Infant and Toddler program.

Another sub-committee issued a report in 1989 stating what they believed should be the goal of the early childhood service coordination system.

> The [committee] believes that a major responsibility of early intervention is to provide support, guidance and direction for parents and to assist them in assuming a greater level of direct case responsibility for their children. While some parents may not desire or be able to assume the full responsibilities of service coordination as defined for the population, all parents are "presumptive" case managers for their children and should be assisted in a variety of ways in assuming a greater level of case responsibility.

Goals for Service Coordination - Part H System

Fox interviewees expressed desire for the current system to change to better meet the needs of the family. Flexibility was a key factor that each interviewee mentioned. "For some families, service coordination might be a semantic service to comply with the law's requirements, while for others it should be extensive coordination and support." There were also consistent statements about the need for the service coordination system to empower the family, as opposed to services based on previous philosophical beliefs that viewed the family as dysfunctional: "What early

intervention should be about is transforming problems into projects and then assisting people to feel mobilized to attempt these projects. If you want a break through in people's actions, you've got to change the way the world occurs for them," explained one interviewee. To rectify the outdated perceptions, some interviewees recommended systematic pre-service education and in-service of case managers.

Some of those interviewed in Fox recommended coordinating with the services already provided by the service coordination division described earlier. Interviewees often stated that the early intervention staff should not and could not be expected to know all the details of services needed for each family. Interviewees acknowledged that the formal case managers in the other divisions have some knowledge not shared by the early intervention staff, such as "how to crack the SSI system" and some other specific content areas.

However, this formal system of service coordination was separate from the Part H system of service coordination. For instance, if a family needed Tier II or Tier III services, they would be referred to that alternative service system and served by that separate system as resources existed to serve them. There was no goal for these services to be part of the early intervention scope. Some people expressed the hope that if a tier II or III service coordinator was to be involved with the family, that service coordinator should "keep in close contact through the telephone or other means" with the early intervention service coordinator.

In Charlie, there was also agreement about the goal of service coordination under the Part H system. The goal frequently articulated in that state was to provide just the right amount of assistance to help families, without making families dependent on the system. There had been considerable discussion by policy makers about the service coordination system. The goal described by one interviewee exemplifies the comments received:

> Effective service coordination means having someone bring together all the services that each child needs. We must recognize the family's own resources and help only to the extent that they want and need. We should develop a system so that case managers can provide a continuum of support.

Although there was consistency among the interviewees about the goals for the service coordination system, there was some discrepancy about how the system should be implemented; the point that generated the most conflicting statements was about who should provide the service coordination services. In some cases, personnel appeared to be guarding their "turf" and maintaining that their agency had demonstrated that they can and do provide cost effective service coordination and so should be the case managers for the early intervention system. Others expressed concern that certain groups not be imposed upon to provide certain service coordination services. For example, "Nurses are afraid if they are assigned as case managers they will get jobs that they don't need to do, like calling meetings together and arranging for times and a place to meet. They don't have enough time now to do their primary tasks." Along the same lines, another said, "If you are using physical therapists as case managers, and you only have five in the whole region, using even 10% of their time as case managers is inappropriate."

The majority of the interviewees in Charlie endorsed a goal of cross agency responsibility for the provision of service coordination services. A representative state was "All agencies should have a role and specified responsibilities for service coordination so that no one is duplicating services."

Charlie's goal initially was to develop policies that each relevant agency would then introduce for rule-making. At the time of the interviews, however, this plan was encountering obstacles that largely appeared to be due to the existence of newly arrived key policy people. This possible failure of a multiple-agency approach to rule

making seemed to be discouraging to many of the key players who had been involved with the planning process since the beginning. Others indicated that interagency conflicts had been obstacles in the past that were overcome and that the present situation might be resolved as well. In any case, if necessary, the regulations for the early intervention system would be promulgated by only one agency, with the intent to apply them to anyone providing service coordination as an early intervention service.

When discussing strategies for implementing their recommendations for service coordination activities, caution was expressed that the explicit goals of shared responsibility for implementation could not occur unless activities were undertaken to support this. State clarification of responsibilities was called for often. "We need a series of interagency meetings at the state level that will clarify responsibilities." One representative strongly urged that no matter what the service coordination system ended up looking like, there was a great need "to assure that the service coordination systems that are developed to address the needs of these children are as compatible, similar and nondivisive as possible. In reality, some variations might be necessary depending on geography, location of the agency or the case managers themselves. But we must avoid providing service coordination services to [some children] that are different [from those provided to others]."

Strategies for Policy Development

Fox developed Part H policies for service coordination using a program subcommittee of the ICC. One of the early issues they confronted was what to do about providers of service coordination services who were not part of the early intervention staff. The subcommittee determined that there was no way to tell others what to do and so they decided to focus on policies that were applicable only to the service coordination provided by the early intervention program of the lead agency. The subcommittee planned to make recommendations to the ICC. The ICC would in

turn provide recommendations to the lead agency. The plan then was for the lead agency to draft official policies.

The strategies that were suggested by the interviewees in Fox for modifying the system were to fine-tune providers' attitudes and approaches. Some expressed a desire to coordinate with the service coordination system that was established in the agency outside of the early intervention system, but details about how this arrangement might occur were not forthcoming as of yet.

Charlie started work on policies for the service coordination system in 1985. Original policies were proposed by a subcommittee of the ICC to a committee of the ICC. The full committee then made recommendations that were reviewed within each agency involved in the provision of early intervention services in the state. The recommendations were piloted, reviewed, and revised, and final standards were developed.

Many interviewees reported that this is an effective system for policy development, because the subcommittee conscientiously seeks and obtains input from the "grass roots" up through the channels of each agency's structure. There is a sense that this system worked because there was broad representation across agencies, local providers, and parents. Interviewees also commented that one of the reasons for the success of this process is the good management techniques of the executive director of the lead agency.

This state is currently using a consultant and at least two sub-committees to review their policies to determine if changes need to be made to respond to Part H or other state specific circumstances.

Specific recommendations to facilitate the change to the Part H system in Charlie included pre-service and in-service training. One interviewee described the need for materials to support this training: "There needs to be a set of instructions, a manual, or a program that is consistent from place to place but flexible enough to be

appropriate to the child's disability and the family's circumstances." One recommendation was for the state "to disseminate a variety of good models where service coordination is already occurring across agencies. Maybe select one model where one agency is assuming the role of single entry point, for example, an early intervention site, and some models where the agency varies depending on the needs of the child."

Predictions by Interviewees about Policies for Service Coordination

Fox interviewees offered little data on which to base predictions in Fox. The sense of the interviews was that some changes are desirable, but how likely it was that such changes would be made seemed uncertain, at best. The recommendation to use and/or coordinate with an existing formal system of service coordination within the agency but outside of the early intervention program appears to be unlikely to happen, given the comments of key policy personnel who downplayed that division's involvement with the Part H system.

Many interviewees noted the need to change providers' perceptions of families and these professionals' attitudes. Mechanisms for making these changes were referred to sparingly, and thus little evidence is available about the likelihood of changing attitudes and approaches to families. There did appear to be a subtle sense of optimism on the part of the interviewees.

The interviewees in Charlie called for statewide and system-wide changes in the delivery of service coordination services. Despite the fact that there were many barriers (primarily the lack of qualified personnel to do the service coordination) to the development of a comprehensive, family-centered, service coordination system, there was a great deal of optimism on the part of all of the interviewees. Most of this enthusiasm was derived from the cultural ethos of this state. "[This state] is open to this. Our people are known for caring. We know each other. This make coordination

easier. We're not smaller geographically, but the smaller population really makes a difference." Another concluded by saying, "[We] are very self-reliant and tend to rely on our own families and communities for resources. Communities are basically tight ... and communities take care of their own."

Critical Factors Regarding Identification in the Development of Policies for Service Coordination

The factors that appear to be influencing the development of policies for service coordination history (Fox, resources, climate (Charlie), policies (Fox), structure, policy development (Charlie) and shared vision are identified below:

History and Resources -- Fox. The early intervention personnel have been providing some fairly low intensity service coordination to families of young children with special needs. The goals of the majority of the interviewees are not so much to change the system as to expand and perhaps to coordinate activities with other entities that provide service coordination. There was a formal and complex service coordination system under other authority, which has personnel, training curriculum, and existing practices available; if the Part H system chooses, it can coordinate with this system.

Resources -- Charlie. This state has service coordination experience upon which to draw as it develops policies that conform with Part H. A shortage of qualified personnel was often identified as a major disadvantage that will need to be addressed in the policies.

Climate -- Charlie. Since this state has a climate of strong local autonomy, whatever policies are developed at the state level will have to allow flexibility at the local level. This strong local influence has also been cited as one of the major reasons for the state's potential for success in this endeavor. There is a strong sense of community, and communities "take care of their own."

Policies -- Fox. The early intervention programs have established policies that guide the provision of service coordination currently. These policies have been determined by the state to be consistent with Part H requirements.

Structure -- Fox. The experience of the pilot sites may be able to provide important data by which the lead agency can make decisions about Part H service coordination policies. There was a subcommittee of the state ICC with designated responsibility for the development of these policies, and this group began discussions about this topic early in the development of the Part H planning phase.

Structure -- Charlie. Because there were some service coordination activities occurring with various agencies, the structure of the ICC (i.e., high level administrators from each of the providing agencies) can be influential to policy development.

Policy Development Processes -- Charlie. With the passage of P.L. 99-457 in 1986, the ICC began efforts to decide if the current standards were still applicable as previously planned. Although interviewees commented that they thought the process of developing the existing standards had been a successful mechanism, some unplanned and uncontrollable events occurred that may alter this ease of coordinated policy development. For instance, there have been personnel changes in key positions. Although careful attention has been paid to keep parents, local providers, and state agency personnel involved in policy development and approval, when major new players become involved in the development of policies after significant work has been accomplished, all previous efforts could be challenged. Since the ICC reported surviving other challenges to coordination, that history bodes well for the future.

Shared Vision -- Fox. The shared vision of the service coordination structure is that whatever system is developed must reinforce the autonomy and integrity of the family. The system should be designed to empower families.

Shared Vision -- Charlie. There was a shared vision for the goals of the service coordination system. However, opinions about specific policies for the implementation

of the service coordination system varied significantly among these key players. Interviewees indicated that issues of "ownership" must be worked out if the policies and programs for service coordination are to be comprehensive and unified throughout the state and across all agencies.

Summary of Results - Service Coordination.

In regard to policies on service coordination, interviewees in Fox focused on the need to make changes in professionals' attitudes towards families, such as promoting a change from considering the family a passive recipient of services to the view that families are basically very competent and sometimes need outside assistance. Otherwise, the goal appeared to be to continue to do what had been done (i.e., have the early intervention staff provide what service coordination they could, given their therapy schedules and other work assignments).

Fox's lead agency had a division within the agency that provided service coordination services to clients who are developmentally delayed, including infants and toddlers and parents of infants and toddlers who are developmentally delayed (i.e., that division had clients who were eligible for service coordination from their division that were also eligible for service coordination under the Part H program). However, there was no discussion by key policy makers concerning the use of, or coordination with this system of service coordination. Neither was there talk of trying to authorize one service coordinator for a Part H family. Thus, families in this state may end up with more than one service coordinator, even though both case managers are authorized by the same state agency.

The case managers of the other division within the lead agency were identified as having knowledge and skills that the early interventionists could not expect to have, such as knowledge of supplemental income programs for which infants or toddlers with disabilities were likely to be eligible. Therefore, because this expertise was not

going to be incorporated for all families within the Part H program, some families not eligible for the service coordination provided to developmentally delayed clients could receive an inferior level of service.

In contrast, the goals in Charlie reflected the desire on the part of the interviewees to develop a family focused system that transcended agency boundaries. There was a dynamic tension on the part of providers between wanting to do things the way they thought best and recognizing the need for state policies to avoid fragmentation and duplication of services and to ensure equity to all families throughout the state. Often, interviewees requested guidance from the state about how to conduct service coordination activities that would still allow providers some flexibility within this guidance.

Table 5

Policy Development for Service Coordination

Fox	Charlie
Goals	
• Be flexible about amount and kind of service delivery.	• Be flexibile about amount & kind of service delivery.
• System should empower family.	• Cross agency responsibility for service coordination.
• Different education and in-service for service coordinators	• State clarification of responsibilities
• Some recommended coordination with other existing Service Coordination activities, others against this.	• Uniform across state.
Strategies	
• Subcommittee of ICC develop recommendations and lead agency draft official policies.	• Prior to 99-457: sub-committee of ICC developed recommendations, reviewed within each agency, pilot recommendations, develop final standards after another review.
• Fine-tune providers' attitudes	•Two sub-committees and an outside consultant review previous policies.
	• Pre-service and In-service training.
Critical Factors	
• History and Resources • Policies • Structure • Shared Vision	• Resources • Climate • Structure • Policy Development Process • Shared Vision

Discussion

The passage of Part H legislation brought states with established early intervention systems face to face with two options. First, they could modify the direction and nature of the previous service delivery system; second, they could continue on the course established by the state prior to the passage of Part H. The biggest changes required by Part H were the identifictaion of family strengths and needs and provision of services to meet the families' needs as they related to the development of the infant or toddler with special needs. Thus , the major difference for states that had been providing early intervention services would be a shift from predominantly child-focused services to a system that was much more responsive to the needs, concerns and priorities of the family. One of the states (Charlie) in this study solidly chose modification, including modification as to how the system interacted with the family. Another (Fox) chose to modify their practices only slightly in order to refine some practices or to comply with federal requirements.

Predictions about which of these processes (or both) will result in successful policies and programs for children and their families in the long term are not possible, but some observations can be made based on the preceding data. Charlie, moving to a more family-focused system, chose an approach that widely opened up its policy development to the public and to the other agencies in the state. The lead agency provided vehicles, eg., focus groups, to allow parents at the local level to recomemnd and to react to policy issues. The early intervention system was seen as a state endeavor and not as another program within the lead agency. This approach resulted in vociferous constituencies who obviously felt that the program was "owned" by them.

In contrast, the personnel administering Part H in Fox determined, with approval of the ICC, that the law required minimal changes to its existing system. This approach has resulted in greater consistencies of the interviewees' responses because they

understand that they will continue to serve children and families as they had been doing.

Personnel in both states evidenced concern and respect for families. Personnel and parents in Charlie seemed to feel more responsibility for the development of the mission, direction, and implementation of the program. The strength and the diversity of their opinions about the entitlement issue indicated that many people throughout the state had considered this issue. In Fox, there was a consensus based on "This is what we have always done."

If a state chooses to use the passage of Part H as a stimulus to re-examine its approach to service delivery, systematic effort might be required to inform constituencies throughout the state of the various options and issues to be considered and to provide these constituencies with a variety of mechanisms to convey their opinions to those who will be making critical decisions. This expenditure of effort and resources appeared as an important priority in Charlie.

Some of the mechanisms Charlie used were: conducting focus groups in regions to receive input and feedback from families, the creation of a mechanism by which providers can discuss these issues with each other and relay their opinions to policy makers, and boards with senior agency personnel who were actively involved in the multiple decisions and implementation of these policies for the early intervention program. This concerted, planned, and comprehensive approach to soliciting and considering recommendations from a variety of populations statewide led to a feeling of ownership by constituents and willingness of high level policymakers to make the necessary changes in order to meet the needs of children and families throughout the state. In addition to systematic communication vehicles, as Harbin (1991) found in her interagency study, soliciting involvement from all strata of personnel (local providers and recipients, mid-level management, and high level policy makers) appeared to be an important strategy in policy development.

The most obvious conclusion that can be drawn from this study is that policy development appears to be much easier if the policies are developed by a single agency and when they impact almost solely on the providers under the direct authority of that single agency. Fox was revising existing practices through rather minor adjustments in attitudes and some practices of existing personnel. In addition, the state was "staying the course" with a predominantly child-focused program, an approach with a relatively long history in this state. Communication seemed to be expedited under these circumstances, if consistency of opinions can be interpreted as a result of shared communication. Charlie, approaching the development of a family-focused early intervention system as a multi-agency responsibility to multiple constituencies, presented a system that was much more complex and, at times, more ambiguous, and as a result, less consensus was shown by interviewees.

While policy development may be expedited by involving only one agency in the policy development and primarily directing the agency's attention to those activities under the agency's direct control, judgement about whether this approach results in policies that promote optimal results for families of infants and toddlers with special needs must be delayed. Multi-agency policy development and implementation appears to be more time-consuming and, at least at some times, more confusing to those who develop the policies, provide services, and receive the services. However, in the long run it will be important to see if the services resulting from this type of policy development better meet the needs of families. The emphasis that the law places on interagency cooperation certainly indicates that the Congress thought that a high level of coordination would be essential to develop a comprehensive early intervention system for infants and toddlers and their families.

Recommended Actions for Policy Development

Whether the state decides to fine-tune its early intervention system with minimal policy changes or to revise its current practices to a greater degree, the following recommendations emerged from this study:

1. Use the passage of Part H to thoroughly re-examine the approach the state was using to provide early intervention services.
2. Inform families, advocates, and providers of the issues and options involved in the provision of early intervention services. Knowledgeable constituencies might be more involved in the policy development phase.
3. Provide multiple vehicles for input from the local level to reach the state policy makers.

4. Identify and invest authority in multiple agencies that provide services to this population. This makes policy development more likely to avoid fragmentation and duplication and to have shared responsibility for the program.
5. Involve personnel from all strata of program implementation and policy making: local providers and parents, mid-level management and high level policy makers.

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